

Cancer patients: their desire for information and participation in treatment decisions

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Summary

The relationship between cancer patients' desire for information and their preference for participation in decision making has been examined. Approximately 77% of the 52 patients reported that they had participated in decision making to the extent that they wished, while most of the remaining 23% would have preferred an opportunity to have greater input. Although many of the patients actively sought information, a majority preferred the physician to assume the role of the primary decision maker. Ethically, the disclosure of information has been assumed to be necessary for autonomous decision making. Nevertheless, the results of this study indicate that patients may actively seek information to satisfy an as yet unidentified aspect of psychological autonomy that does not necessarily include participation in decision making.

Introduction

Recently, much attention has been focused on the need for health professionals to communicate with and provide information to patients, in order that patients may participate in informed decision making about their health care^{1,2}. This emphasis stems, primarily, from ethical, legal, and social concerns. Ethically, there has been a change from a paternalistic philosophy of care to one in which autonomy and patient self-determination are promoted^{3,4} and the provision of information is, obviously, a central issue. Legally, there are formal requirements concerning the exchange of information between the patient and physician particularly with regard to informed consent documents⁵. Socially, there has been a growing movement advocating the view that the patient is a health care consumer with rights to information, interaction with health professionals, and participation in decision making⁶.

Several studies have examined the desire for information and participation in decision making from the patient's point of view⁷⁻⁹. For example, Cassileth *et al.*⁷ demonstrated a strong association between preference for information and participation in health care, particularly by younger patients. Strull *et al.*⁸ found that physicians, caring for hypertensive patients, overestimated their patients' desire for participation in decision making and underestimated their desire for information. Krantz *et al.*⁹ suggested that the desire for information and behavioural involvement in medical care are relatively independent factors. It would appear that the relationship between patients' preferences for information and the use to which such information is put is not clearly understood. Furthermore,

questions arise about the notion that the desire for and provision of information ultimately leads to involvement in the decision making process.

The purpose of this study was threefold. We wished to compare (i) two methods of determining how actively 52 cancer patients sought information about their health status, (ii) patients' 'ideal' preferences for participation in treatment decision making with their 'actual' experience, and (iii) the desire for information with the actual role patients took in their treatment decision making process.

Methods

The general plan was to use two different questionnaires to assess how actively a group of cancer patients sought information regarding their health status, to assess the internal consistency of each of the methods, and to examine the association between these instruments. As well, an assessment of preference for degree of participation in treatment decision making was determined and the relationship of participation in decision making to information seeking was explored.

Subjects

A convenience sample of 52 outpatients participated in this study. All patients had been admitted to the Princess Margaret Hospital Lodge, an ambulatory care facility for patients from various parts of the province of Ontario who require post-surgical treatment for cancer.

Patients were eligible if they understood spoken and written English, were receiving treatment for a primary malignancy, and consented to take part. These patients were all at an early phase in the course of their disease. Because participants were selected at random from the Lodge roster, it was unlikely that the subjects were provided with additional facts or help.

Questionnaires

Health Opinion Survey (HOS) In 1980, Krantz and colleagues reported on the development and validation of a questionnaire to measure preferences for information and for behavioural involvement in medical care⁹. A binary agree-disagree format was used to elicit responses to 16 statements, 9 of which were concerned with attitudes toward self-treatment and active behavioural involvement in medical care (behavioural involvement=B scale). The remaining 7 statements focused on the desire to ask questions and to be informed about medical decisions (information=I scale). As well as these two subscales, a total score measuring a composite attitude toward treatment approaches was determined.

SOME PATIENTS PREFER TO HAVE VERY FEW DETAILS ABOUT THEIR ILLNESS AND TREATMENT WHILE OTHERS PREFER TO HAVE AS MANY DETAILS AS POSSIBLE. PLEASE MAKE A MARK ACROSS THE LINE AT THE POINT THAT BEST DESCRIBES YOU AT THIS TIME.

Prefer as few details as possible _____ Prefer as many details as possible

HOW MUCH INFORMATION DO YOU FEEL YOU HAVE ACQUIRED ABOUT YOUR ILLNESS AND TREATMENT TO DATE ?

Minimum amount _____ Maximum amount

IN GENERAL, HOW WELL DO YOU UNDERSTAND THE INFORMATION YOU HAVE ACQUIRED ?

No understanding at all _____ Complete understanding

HOW SATISFACTORY IS THIS INFORMATION IN MEETING YOUR NEEDS ?

Extremely unsatisfactory _____ Extremely satisfactory

IN GENERAL, HOW ACTIVE HAVE YOU BEEN IN OBTAINING DETAILED INFORMATION ABOUT YOUR CURRENT ILLNESS ?

Generally, I have not actively sought this information _____ Generally, I have actively sought this information

Figure 1. Examples of global linear analogue self assessment scales used to assess information seeking regarding health status. All scales range from 0 mm (left side) to 100 mm (right side)

Information Seeking Questionnaire (ISQ) A questionnaire containing 18 linear analogue self-assessment (LASA) scales was developed. Thirteen scales represented different kinds of information a patient might wish to have about cancer and its treatment. These items were derived from the Information Styles Questionnaire developed by Cassileth *et al.*⁷ and a patient panel who were asked to verify and/or suggest additional items. Five other LASA scales of a more global nature were presented. These included an overall assessment of amount, detail, and understanding of information, a global assessment of the degree of active information-seeking, and the satisfaction with details acquired. Examples are shown in Figure 1.

Preference for participation in treatment decisions questionnaire A questionnaire, adapted from one developed by Strull *et al.*⁸, was designed to assess each patient's preference for participation in treatment decision making under 'ideal' circumstances. As well, using the same scale, the patient indicated how his/her treatment decisions were 'actually' made. Preferences were measured on a 5-point rating scale ranging from the physician assuming full responsibility for decision making to the patient assuming this role (see Figure 2).

Statistical analyses

Information seeking methods Internal consistency was examined using Cronbach's alpha¹⁰ for the ISQ and the Kuder-Richardson 20 test¹¹ for the HOS. The validity of the ISQ was examined using the HOS; the former focuses on information seeking in relation to the cancer experience, while the latter measures preferences for information and behavioural involvement in general medical care. The association between scores on the ISQ and the HOS was

AFTER THEY HAVE ALL THE INFORMATION THEY NEED ABOUT THEIR ILLNESS AND POSSIBLE TREATMENTS, SOME PATIENTS PREFER TO LEAVE DECISIONS ABOUT THEIR TREATMENT UP TO THEIR DOCTOR, WHILE OTHERS PREFER TO PARTICIPATE IN THESE DECISIONS. PLEASE CHECK THE STATEMENT THAT BEST DESCRIBES WHAT YOU BELIEVE WOULD BE IDEAL.

- _____ The doctor should make the decisions using all that's known about the treatments.
- _____ The doctor should make the decisions but strongly consider my opinion.
- _____ The doctor and I should make the decisions together on an equal basis.
- _____ I should make the decisions, but strongly consider the doctor's opinion.
- _____ I should make the decisions using all I know or learn about the treatments.

Figure 2. The 5-point scale for rating preference for participation in treatment decision making; 'ideal' situation. (Adapted from Strull *et al.*⁸)

determined using the Spearman rank correlation coefficient. A non-parametric correlation was used because of a cluster of high scores on the ISQ.

Participation in decision making A chi-square test was used to determine the relationship between 'ideal' preferences and 'actual' decision making experience.

To test for a trend of ISQ total scores across the different levels of 'ideal' preference for participation in decision making, Jonckheere's test was performed¹². Only the ISQ scores and not the HOS scores were used in this assessment, because the ISQ and the 'ideal' participation questions are both focused on the current illness.

Results

The data were collected over a one month period and no patient who was asked to participate refused. The participants included 35 women and 17 men. Forty-seven (90%) were receiving radiation therapy while the remaining patients were undergoing chemotherapy. The mean age of the group was 48.5 years (s.d. ± 13.8). All had undergone biopsy for diagnostic purposes. Sites of malignant disease included breast (17), head and neck (9), female reproductive (7), prostate (5), lymphoma (6), and others (8). This group was representative of the usual composition of Lodge patients who total about 100 at any given time.

ISQ and HOS

Table 1 includes the mean scores of the global scales of the ISQ and HOS. In general, patients were active in obtaining information, as indicated by the reasonably high scores on the ISQ scales. They also appeared satisfied with the information acquired. The mean score on the HOS behavioural involvement (B) subscale (1.90, relative to a maximum possible score of 9) was low in comparison with the mean score on the HOS information (I) subscale (3.71, relative to a maximum possible score of 7).

Cronbach's alpha coefficient was 0.88 for the ISQ. The Kuder-Richardson 20 coefficients for the HOS were as follows; 0.75 for the I subscale, 0.68 for the B subscale, and 0.74 for the entire scale. Both methods appeared to be internally reliable.

The global scale of the ISQ, which represented an overall assessment of how actively information was sought, was compared to the HOS total score and the HOS information subscale score. The Spearman's rank correlation coefficients were 0.49 ($P < 0.001$) and 0.48 ($P < 0.001$) respectively. Thus, the correlation between

Table 1. Summary statistics for the Information Seeking Questionnaire (ISQ) and the Health Opinion Survey

	Mean	s.d.	Median	Range
<i>ISQ global LASA scales*</i>				
ISQ summary score	72.6	29.5	86.0	0-100
Amount of information acquired	73.2	22.9	77.0	8-100
Desire for details	88.9	15.4	95.5	33-100
Understanding of information	77.6	19.8	79.5	22-100
Satisfaction with information	79.6	18.3	85.5	26-100
<i>Health opinion survey</i>				
I scale score	3.71	2.13	4.00	0-7
B scale score	1.90	1.87	1.50	0-8
Total score	5.62	3.12	5.00	0-15

*The range of scores for LASA scales=0-100; for the HOS I scale, 0-7; HOS B scale, 0-9; and HOS total score, 0-16. A high score indicates greater information seeking, involvement, etc.

the ISQ and HOS scores, although statistically significant, did not exceed 0.50.

Participation in treatment decision making

The data were aggregated and examined according to preference for *participation* (i.e. the patient assumes some responsibility for the decisions regarding treatment) versus *non-participation* (the physician assumes sole responsibility) for both the 'ideal' and 'actual' experience. This aggregation of the data was done to avoid small numbers appearing in some cells of the table. When the aggregated data were assessed, 40/52 patients reported congruence between their 'ideal' and 'actual' experience (25 reported congruence in relation to participation, and 15 in relation to non-participation). The chi-square value for the data was 16.3 ($P < 0.005$) indicating a significant association between the 'ideal' and 'actual' experience. Of the patients who reported lack of congruence, 10/12 reported an 'actual' level of experience that was less than their 'ideal' and 2/12 reported a level of experience greater than their 'ideal'. Thus, significantly more subjects reported an 'actual' level that was less than their 'ideal' ($P = 0.039$, binomial distribution¹³).

The patients' responses to the ISQ were compared with their responses to the questionnaire about 'ideal'

Table 2. Comparison of responses to the Information Seeking Questionnaire with those about 'ideal' participation in decision making

<i>Ideal' level of participation*</i>	Median ISQ score*	Number of patients
1. Doctor alone	75.0	17
2. Mainly doctor	79.0	16
3. Equal basis	88.5	14
4. Mainly patient	91.0	5
5. Patient alone	N. A.	0

*See Figure 2.

*Significantly associated with level of participation, on the basis of Jonckheere's test¹², $P = 0.020$.

participation in treatment decision making. The results are shown in Table 2. A trend toward increased information-seeking information with increased levels of preference for participation in decision making was noted ($P = 0.020$). However, 63% of the patients, although showing relatively high ISQ scores (above 70), preferred little or no involvement in decision making (see participation levels 1 and 2, Table 2).

Discussion

The two methods for determining how actively patients sought information about their health status, the ISQ and the HOS, were internally consistent. The HOS results obtained here compare favourably with the original report of internal reliability by Krantz *et al.*⁹.

When the ISQ global scores were compared with the HOS total scores and the HOS information subscale scores, the associations were statistically significant but modest in magnitude (rank correlation coefficients near 0.5). This significant association provides some evidence for the validity of these methods as measures of preference for information. The modest magnitude of the associations is probably a reflection of the fact that the ISQ specifically referred to the cancer experience, while the HOS focused on general health care.

Approximately 77% of the patients had the opportunity to participate in decision making about their treatment to the extent that they desired. Most of the remaining 23% would like to have had greater input. An interesting feature of the data was that 63% of patients felt the physician should take the primary responsibility in decision making, 27% felt it should be an equally shared process, and 10% felt they should take a major role.

These results may resolve some of the apparent discrepancies revealed by earlier work⁶⁻⁷. In agreement with the data of Cassileth *et al.*⁷, there was a statistically significant positive association between information seeking score on the ISQ and level of preference for participation in decision making. However, the median ISQ score was rather high even for the 63% of patients who felt that the physician should take primary responsibility in decision making. These results indicate that patients' preferences for information may be related to factors other than their desire for behavioural involvement in decision making.

One should note that patients in this sample were attending a cancer hospital and were exposed to programmes offering information, opportunities to discuss concerns with health professionals, and a patient library. Thus, information exchange was promoted, and possibly patients provided socially acceptable positive responses. However, there was a good range in the data, in that some of the 52 respondents felt that they had been quite active in seeking information while others felt they had not.

Why did most of these patients seek information if in fact a majority preferred the physician to assume the role of primary decision maker? Our results suggest that many patients may actively seek information to satisfy an aspect of 'psychological autonomy' that does not necessarily include participation in decision making. Katz¹ has defined the concept of 'psychological autonomy' as the capacity of a person to become informed so that he/she may

exercise the right to self determination. Although armed with information, some patients may choose to express their autonomy by authorizing their physicians to make all decisions, and thus decide not to decide¹⁴. The basis for such a choice merits investigation. For example, patients' anticipation of regret for a bad decision could lead them to ask to have the decision taken out of their hands¹⁵.

There will, of course, be patients who feel they do not have sufficient knowledge to make decisions concerning their treatment, particularly involving complex, highly technical treatment programmes of the kind used in cancer therapy. On the other hand, there will be those who feel such treatments are not without risks and, even though they may not have complete knowledge, are prepared to decide what they will or will not tolerate.

The desire of some patients to relinquish primary responsibility for treatment decisions highlights a potential conflict between the ethical principles of autonomy and beneficence. At one extreme is the view that paternalistic physicians attempt to impose a beneficent approach on reluctant patients, who would, if adequately consulted, prefer a more autonomous approach to decision making. Our results are compatible with the reverse of this extreme stereotype. One can interpret the results to indicate that professionals, in an attempt to encourage informed, autonomous decision making, may provide information which many patients may indeed desire to have. At the same time, although most patients may prefer to have their autonomy respected in relation to the provision of information, a majority may also wish to have the decision making done by others, that is, to authorize their physicians to take a more beneficent approach in relation to actual decision making. Obviously, there are varying weights or values assigned to these (and other) major ethical principles by both health professionals and patients, and these values may vary according to the circumstances. Autonomy may be given a high weight by patients in relation to the aspect of decision making concerned with provision of information, but then subsequently be given a lower weight in relation to taking personal responsibility for the final choice of treatment. These relative values, and the factors that may influence them, deserve further study.

In summary, most of the patients who participated in this study felt that they had actively sought information, yet a majority preferred to relinquish the decision making role. These results are at odds with a philosophy of care which advocates a consistent, unvarying dedication to the promotion of patient autonomy and self determination. Such an inflexible philosophy of care may actually conflict with less consistent, more situation-dependent preferences on the part of many patients.

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